

Summary Report for Leicester Community Outreach Participants – February 2025

1. Introduction

In February 2025, a Community Outreach event was held in Leicester, attended by the Cancer Theme of the Nuffield Department of Primary Care Health Sciences (NDPCHS), Oxford University, in partnership with local organisations, GPs and individuals.

The aim of the event was to explore views and experiences of the public about cancer testing in NHS General Practice.

This report provides a summary of the event, the views participants shared and our planned future work with local communities.

2. Partnership Building

Initial contact was made with local community groups, charities, health and statutory services to promote the Community Outreach consultation event. Promotion was carried out through a number of ways including publishing a brief article for online voluntary sector newsletters and attending community events to network with both individuals and organisations. These included events arranged by Healthwatch Leicestershire, and the City Retreat. Participation was also undertaken in an online meeting of the Health and Wellbeing Neighbourhood forum to further promote the event.

The Community Liaison Manager of the Cancer Theme identified Voluntary Action Leicester as a suitable venue for the event and an appropriate room was hired. Contact was established with organisations who could provide health and wellbeing information to people attending. On the day partner organisations included:

- Apnapan – (cancer support group)
- Wellbeing Champions (Leicester Public Health)
- Jamila's Legacy (mental health support)

The event started with an introduction from Dr Tanvi Rai, of NDPCHS. Research GP Brian Nicholson spoke about the role of general practice in early detection of cancer. The public information video from Pancreatic Cancer UK was screened to assist with discussions. We showcased how non-invasive biomarker tests using blood, breath and urine would be used by displaying the actual tests. This was followed by an informal discussion where participants shared their experiences of accessing primary care services, including participants that had previously been diagnosed with cancer.

3. Findings from Participants

The participants talked enthusiastically about their experiences of accessing GP care and the challenges they face. Key Issues:

- Feeling of bouncing between services and lack of joined working/communications between health services. Participants felt they had to “chase services to get results of tests”.
- Difficult to get face-to-face GP appointment, receptionists obstructing access. Not being confident in using computers also resulted in some people perceiving there were differences in opportunities to access health services.
- Experiences of anxiety reported whilst people waited for results and once given the “all clear”. How can they be supported? Participants identified a potential role for primary care or cancer charities during this period.
- Terms and names of tests can be confusing and need explaining – positive and negative can be misinterpreted by patients, so need clearer explanations of what tests mean.
- Challenges of understanding metastatic cancer, “why would breast cancer be in lungs?”
- Keen interest in which cancers could be detected by multi-cancer tests and the timeframe for when they could access multi-cancer tests as patients.
- Frustrating for patients when felt “fobbed off”, with early symptoms which then go on to become cancer. Resulting in loss of confidence in health services as “one bad experience can affect others because ‘people talk’.”



Discussions in Leicester.

4. Next Steps from the Cancer Theme

By reviewing the feed-back we gathered from Leicester and the other locations we have committed to the following to try and address some of the concerns expressed above:

- Producing a video explaining what cancer is, what metastases is and why it spreads.
- Engage with local GPs to attend our future events, to advise patients of commonly used terms to communicate effectively with health professionals.
- Producing a glossary of commonly used terms in cancer testing i.e. positive, negative test results, and terminology on health body literacy (being aware of own body and any changes).
- Arrange future events in each location to promote ongoing research studies, such as the ARMADILLO study (study of effectiveness of multi-cancer tests in primary care). These follow up events will take place between October 2025 – April 2026.

For further information or for a copy of the full report, please contact Haleema Aslam (Cancer Theme, Community Liaison Manager, Nuffield Department of Primary Care Health Sciences (NDPCHS), Oxford University) via: haleema.aslam@phc.ox.ac.uk